

# Family Caregiver

Sharing Information & Giving Support to Hawai'i's Family Caregivers

VOL. 1 • ISSUE 1 • 2002 • THE EXECUTIVE OFFICE ON AGING • STATE OF HAWAII

## A Message From Marilyn Seely

**Dear Caregivers,**

**C**aregivers across the state deserve the heartfelt thanks of a grateful community. You provide the backbone of support for frail family members and close friends.

We believe you are under-appreciated and your contributions often go unrecognized. Most of you aren't seeking special recognition for what you tell us is, "just taking care of family," but you are the most vital part of long-term care. Without you, we don't know what would happen to the thousands of frail folks who need help.

As more people join your ranks, we're beginning to see real movement towards being able to offer the support and encouragement you deserve. The National Family Caregiver Support Program under the Administration on Aging is a milestone in this movement. It has provided much needed funding to fulfill the promise of support for caregivers.

This new newsletter is just one way we plan to help you. But we need to hear from you to make sure we are on track. This is a two-way street when it comes to understanding how best to care for our frail elders. Let's learn from each other.

*With warmest aloha, Marilyn Seely*



*Marilyn Seely,  
Director, Executive  
Office on Aging.*

## Karen's Story: A Caregiver's Journey



*Karen Koles and her  
father Charles Kawano.*

*by Karen Koles*

**O**ver 10 years ago, Dad suffered a massive stroke during surgery, which left him totally dependent on others for his survival. Our family agonized between committing him to a nursing facility or caring for him at home. Late one night I confided in a compassionate nurse and asked her what she would do if he were her dad. Without hesi-

tation she said, "I would take him home and love and care for him for as long as the good Lord sees fit to let us have him. It won't be easy, but you'll never regret it." Our family decided to take Dad home, and began a crash course on how to do tube feedings, give bed baths, perform range of motion exercises, and how to manage bed to wheelchair to car transfers.

Dad, Mom, and I moved in with my sister Carolene's family because we knew that in spite of the crowded conditions, we needed the *kokua* that each family member would contribute. Mom, 81

years old and healthy, took care of Dad during the day while the rest of us were away at our full-time jobs. I took over after my work day ended, including the night shift. My sister Carolene ran the household and supplied respite. Her 11-year-old son Jason, quickly learned to do diaper changes and helped with the heavy lifting and turning of his Papa. David, at nine years of age, had the chore of  
*(Continued on page 2.)*

# Karen's Story: A Caregiver's Journey

(Continued from page 1.)

emptying Papa's trash and caring for the family pets. Dad's sister Mitsuko came daily to keep Mom company and to help care for her brother.

Even with the entire family pitching in, we still required outside help. A home health aide came, and we were able to get help from a bathing service as well until we no longer qualified for the services. Since then, Dad has been under our care. Thankfully, we have a geriatrician who makes home visits. Hospitalizations have been few and far between, and the occasional trips to have his G-tube changed

have been accomplished via Handi-Van and HandiCab.

Two years after Dad's stroke, Mom required heart surgery. Mom, Dad, and I decided to move back to my home, which gave us much needed space. Mom soon required almost as much care as Dad, but she refused to hire outside help. Jason moved in with us during his senior year in high school, and was my dependable assistant during Mom's final year while Carolene and David continued to offer respite. Mom passed away in August, 1998, and in September, Carolene and David moved in with us. I was still teaching, Carolene was a school administrator and both boys were now full-time college students. Again, we quickly realized we needed outside help, and through a professional caregiver friend, we found an excellent licensed agency which has since supplied care for Papa three days a week.

Our decision to care for Dad, and later Mom, at home has not been without problems. My biggest personal conflict came with the inevitable role reversals. Social isolation was also a problem, admittedly



of my own making. It became easier to just stay at home instead of having to answer Mom's questions: "Where are you going?" "When will you be home?" "Do you really have to go?" It is no wonder invitations eventually ceased after I made one excuse, then another, for not being able to join friends for occasional outings.

But caregiving has its hilarious moments, too. One day we decided that a shower for Dad would feel so much better than a bed bath, and embarked on this adventure with the precision of a military maneuver. We set up a wading pool in the kitchen, hooked a hose to the faucet, then placed Dad in his hydraulic lift. We managed to swing him over the wading pool, then turned on the water. Dad didn't take too kindly to this makeshift shower and started to wig-

gle. Holding on to him was akin to hugging a wet seal. We beat a hasty retreat with the troops slipping and sliding along a trail of soapy water all over the kitchen floor and the family room carpet, all the way back to the security of his bed. We voted never to attempt wet baths ever again.

Caregiving has required considerable sacrifice for our family, but it has been more than offset by the many benefits we have reaped. All of us have learned to be more patient, considerate and humble. But we are also realistic, and the words exhausting, thankless, unrelenting, sleep-deprived and life-changing also come to mind. It has been so very touching to watch Jason and David interact with and care for their grandparents, and develop into responsible young adults.

## Upcoming & etc...

### **An thou shalt honor... Caring for Our Aging Parents, Spouses and Friends**

2-hour PBS documentary celebrating and exploring the health care issue of long-term caregiving in America. Scheduled to premier Wednesday, October 9, 2002, 7:30 - 9:30 p.m. on KHET.

### **The Hawai'i Senior Fair**

Friday, Saturday & Sunday  
September 27, 28, 29, 2002  
Blaisdell Exhibition Hall

### **Hawai'i Pacific Gerontological Society's Caregivers Conference**

Friday & Saturday  
November 1 & 2, 2002  
Ala Moana Hotel

### **Do you have something to share?**

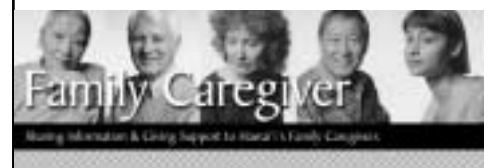
If you have an interesting story, helpful tip, easy and healthy recipe, poem, etc. to share, we would like to hear from you. Send your information to us:

The Executive Office on Aging  
Caregivers Resource Initiative Project  
250 S. Hotel St., Suite 406  
Honolulu, HI 96813  
E-mail: [eoaa@mail.health.state.hi.us](mailto:eoaa@mail.health.state.hi.us)

(Due to volume, we can't print all submitted materials and will not be able to return pho-

tos or written materials. The Executive Office on Aging reserves the right to print what is deemed appropriate for the newsletter.)

**Look out for the next issue of Family Caregiver, scheduled to be released in November 2002.**



The Executive Office on Aging is the state agency whose mission is to assure the well-being of Hawai'i's 200,000+ adults age 60 and over.



E LOA KE OLA  
MAY LIFE  
BE LONG

**Benjamin J. Cayetano**  
Governor

**Marilyn Seely**  
Director, Executive  
Office on Aging

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Chair, Policy Advisory  
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**[www.hawaii.gov/health/eoa](http://www.hawaii.gov/health/eoa)**

# Join the Hawaii Family Caregivers Network

**T**he State of Hawaii's Executive Office on Aging and its partners are developing the Hawaii Family Caregivers Network to enhance family (informal and unpaid) caregiver support efforts.

## What is the Network for?

- To provide a coordinated means to get information out to family caregivers on a number of issues such as services, caregiving tips, legislation and training opportunities.
- To provide a coordinated means for family caregivers to comment or respond to family caregiving needs and issues.
- To gain information on the diversity and complexity of family caregiving issues in Hawai'i. Network members may serve as a vital source of information to researchers on caregiving problems and issues specific to Hawai'i. (Research participation of network members would be strictly voluntary.)

## What are the benefits of joining?

- To get information on national,

state and local caregiving issues.

- To comment on and provide information on family caregiving issues.
- To receive **free** newsletters on family caregiving issues.

## Who should join?

- Any family (informal and unpaid) caregiver to a senior (60 years & older) family member, friend or neighbor.
- A grandparent who is 60 years

and older caring for a dependent grandchild.

If you are interested in joining, please complete the enrollment form below and mail it to: The Executive Office on Aging at 250 S. Hotel St., Suite 406, Honolulu, HI 96813; or fax it to (808) 586-0185. Please call (808) 586-0100 if you have any questions.

*We will not share any coalition member's personal information with other organizations.*

### Hawaii Family Caregivers Network • Membership Sign-Up

Caregiver's Name: \_\_\_\_\_ Phone No. \_\_\_\_\_

Mailing Address: \_\_\_\_\_

E-Mail Address: \_\_\_\_\_ Age: \_\_\_\_\_ Male/Female: \_\_\_\_\_

Who are you caring for (e.g. mother, uncle, neighbor, etc.): \_\_\_\_\_

How long have you been the caregiver? \_\_\_\_\_ Are you the only caregiver? \_\_\_\_\_

How many hours (approximate) of care per month do you provide? \_\_\_\_\_

# Getting the right information on your medication

by *Randolf Oba, PhamD*

**F**or most patients and their caregivers, medications pose an often complicated and confusing proposition. Two very obvious sources of information are often overlooked. One is the physician. People are often so pre-occupied with the excitement and anxiety of the moment when visiting a doctor's office that they forget any questions they might have had. They also don't want to waste the doctor's time with what they consider to be trivial questions. On the contrary, doctors very much want patients to know what they are taking and why. Your doctor is one of the best sources of information. One suggestion is to immediately write down any questions that come up. Frequently after leaving a doctor's office, many questions

will come up. Write them down. You can call the office later to get the answers. It is important that you understand what your medication is for and what side effects and adverse reactions might be expected.

Another source of information are pharmacists. While at your pharmacy, you can ask a pharmacist, who is trained to know about medications. They can tell you about most of the major side effects and adverse reactions. Pharmacists can also provide information on drug interactions. It's impossible to remember everything about medications. However, most pharmacies have drug information either in extensive reference books or computer data bases. Pharmacists can help you avoid drug interactions, while you can become more educated about the drugs and their side effects. Some pharmacies can provide you with

printed information to take home.

If you are seeing several different physicians, make sure that your physicians are all aware of this fact. Also, if you are taking medications prescribed by these physicians, they should all be made aware that you are taking these medications. Don't automatically assume they talk to each other and are aware.

Helpful questions to ask:

- What is this medication being used to treat?
- What are the most common side effects?
- Can I take this medication with food or on an empty stomach?

Lastly, if you are experiencing dizziness, drowsiness, nausea or any other symptoms, please consult your physician or pharmacist. It might be because of your medications.

## Featured Caregiver Support Group

### Eldercare Support Group

Contact: Karen Koles

Pager: 299-1444

**W**hen we first started this journey called Caregiving, we searched unsuccessfully for a support group that would meet our needs. Mom and I enrolled in a state-sponsored class for caregivers where we met other caregivers. Our last session was the Saturday following Hurricane Iniki where we decided to start a support group of our own—without the guidance of professionals. We must be doing something right as we have been meeting on the last Saturday of each month (except December) for almost 10 years.

We occasionally invite guest speakers, but usually our meetings involve sharing personal experiences, crying together and encouraging each other with reminders that we are not alone in this experience, and that some other caregiver is in a worse situation. We also support each other

during the inevitable periods of grief. We tell each other which vendors to avoid, share information we have learned from seminars and workshops and help each other problem solve by sharing what has worked for us. We tell each other where to buy diapers, which agencies to contact for specific help and share a pot luck meal during each gathering.

We always welcome past, present,

and future caregivers. We may not know all the answers, but by putting our heads and hearts together, someone in the support group will know where to go for help, information or possible solutions.

A website is currently under construction, thanks to one of our members. If you would like more information about our meetings, please page Karen at 299-1444.

*Sometimes*

*When I'm sitting in the living room,  
I'm suddenly filled with unexplainable joy,  
Joy that begins from deep within  
And slowly seeks its way toward every pore  
Of my body that has become one  
With sadness, hopelessness,  
fear and pure exhaustion.*

*How can this be,*

*This overwhelming surge of joy  
That leaves room for nothing else  
When my mother*

*Is sitting here in the same room,  
Silently studying her hands,  
Occasionally turning, turning  
Her opal ring on her ring finger?*

*How can I be filled with such pure joy  
When the presence of my mother  
Reminds me of why we are both here?  
What is this mysterious purification  
Of my soul? What can it be  
But the presence of God,  
Whispering, "I am here."  
I weep tears of joy  
For the two of us.*

**—Frances H. Kakugawa**

*Source: Kakugawa, Frances H., Mosaic Moon, Watermark Publishing. Available at bookstores in Hawaii and through Watermark Publishing.*

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MAY LIFE BE LONG